NARRATIVE OF AN AIDS PATIENT

Summary of M & M: Present: Resident with primary responsibility for case; several physician faculty who had had contact with patient during hospital stay; two behavioral science faculty; the referring community physician

Several issues of note emerged from the discussion: 1) discrepancies between resident's information and community physician's information:
a) resident - pt. had no AIDS support system
b) physician - pt. linked up with AIDS Project LA, which is why he expressed no interest in help from social worker in this area
c) resident - mother and father of pt. spoke no English (Spanish)
d) physician - father spoke English well, mother understood well

Pt. initially was admitted to the hospital with his c.p. (community physician) suggesting aggressive treatment. The cp felt pt's weight loss had reached a critical point, beyond which recovery was unlikely. However, since this was his first hospitalization, cp felt hopeful pt. could be stabilized. Pt. entered the hospital with the understanding that a central line would be placed so he could receive perienteral nutrition, and that this was the primary purpose of the hospitalization. Pt. already had significant suspicion of the medical system, which he avoided except for contact with his cp, himself gay, and a provider of services for many homosexual AIDS patients. The cp also admitted he would not have sent the pt. to this hospital if the pt.'s insurance status had been different. Thus both pt. and his physician were already somewhat alienated from the medical system prior to pt. admission.

Cp described pt. as difficult, often demanding and exploitive of his parents, with whom he was currently living. Mother did everything for him, and refused suggestion of assistance. Pt. was often negativistic and defiant, as well as in considerable denial about his disease.

Instead of a quick in-and-out procedure to receive a "life-line," as he had expected, the pt. ended up 10 days in hospital, with multiple consults, but no line placed. By the time surgery saw him, they evaluated him as an unsuitable candidate for the procedure. At that time, the pt. was refusing any oral medication and was requesting simply to go home to die. Pt. left AMA and died about 10 days later.

Cp appeared to have many feelings of guilt and anger. He stated bluntly that he would never admit another AIDS pt. to UCI. He was currently exploring alternative outpatient solutions to line placement. Cp also said that he had not taken a more active leadership position regarding his pt. out of a reluctance to embarrass the family medicine department in relation to other departments and the hospital.

Issues: What happens when there is a significant degree of alienation in both pt. and referring physician from the system supposed to render aid?

What are the most likely points for the system to fail the patient?

What were the sources of the patient's and CP's alienation and hostility?

What was the view of hospital staff toward this patient?

Focus of Inquiry

internal process forms some boundaries
imp. later for how your research will be judged -
if your approach is ethical, no hidden agendas
practicing reflexivity - destructure
circular process - feed + feedback

* what will this mean for people involved in study?
can't talk to all people in system
inviting interference - challenge beginning premises
* what is input?

~~Question~~ Question must fit the paradigm of naturalistic research

Sampling

end pt. - recurring themes
have looked for + incorporated disconfirming data
matrices - how categories might interrelate
theory - your starting feelings, questions
small sample - 6-12
what did I care about in this case?
If focus is research, if focus is pt.

NARRATIVE OF AN AIDS PATIENT

Admitting History: Patient was a 29 year old Mexican male with a 2 year history of HIV+ serum, treated with AZT. At the time of contact with his primary physician, he was worked up for persistent fevers, when MAI (bone marrow) and PCP were also discovered. He was placed on INH, rifampin, ethambutol, colfazamine, ciprofloxacin, and home IV pentamidine. His admitting symptoms were nausea, vomiting, anorexia, weakness, dizziness, and acute weight loss over a 2 week period.

Social History: Patient had a homosexual orientation. His lover had died of AIDS the previous year. He was currently living with his parents, both of whom were also Mexican and primarily Spanish-speaking. His primary physician described the patient as difficult, often demanding and exploitive of his parents. Mother "did everything" for the patient, and refused suggestions of assistance. The patient was often negativistic and defiant, as well as in considerable denial about his disease. The patient had some involvement with AIDS Project LA, and one of their volunteers was in the process of seeking Durable Power of Attorney for the patient.

The primary physician, whose practice consisted largely of AIDS patients and who was gay himself, wanted "everything possible done" for his patient, since this was his first hospitalization and he had only recently decompensated. "Treat him aggressively and we may be able to make a difference in the course of his disease," was the request of the PMD.

Hospital Course: The patient entered the hospital with the understanding that a central line (Hickman catheter) would be placed so he could receive perienteral nutrition, and that this was the primary purpose of the hospitalization. The patient referred to the catheter as his "life-line." The patient already had significant suspicion of the medical system, which he avoided except for contact with his PMD. The PMD also admitted he would not have sent the patient to this particular hospital if the patient's insurance status had been different. Thus both patient and his primary physician were already somewhat alienated from the medical system prior to patient admission.

The patient was admitted to the general medical floor. Infectious disease, gastrointestinal services, nutrition and social services consults were obtained. A surgery consult regarding placement of a Hickman catheter was also obtained. The patient was initially unable to eat, due to nausea, vomiting, and weakness. This was eventually controlled with discontinuance of certain medications and he was able to tolerate small amounts of food.

Meanwhile, infectious disease recommended that the patient have a repeat bronchoscopy and biopsy of the lung to identify a cavitation in the left upper lobe. At this point, the patient refused all invasive procedures. He also refused further consults. Simultaneously, the surgical team felt the risks of placing a Hickman catheter outweighed the benefits and decided not to perform the procedure. The patient continued to accept IV medications, but refused oral medications because of painful oral thrush.

A psychiatry consult was obtained which concluded that the patient showed some evidence of cognitive deficit in memory and concentration, denial tendencies, and the possibility of dementia or an HIV-related brain infection. They recommended CT scan, lumbar puncture, EEG, and

psychometric testing. The patient refused all further studies.

By this time, the patient had been hospitalized for 10 days. Because of decreases in his sodium levels, it was recommended that he remain in the hospital. The patient signed out AMA despite imbalanced electrolytes. This decision appeared to have the support of the mother. Father assumed a more remote and passive role. The patient returned home on a medical regimen and planned participation of the VNA and social services. The patient died 10 days later.

The Primary Physician: The PMD evinced many feelings of guilt and anger. He stated bluntly that he would never admit another AIDS patient to this hospital. He was currently exploring alternative outpatient solutions to line placement. The PMD also said that he had not taken a more active leadership position regarding his patient out of a reluctance to embarrass the family medicine department in relation to other departments and the hospital.

The Resident: The resident was confused and distressed by the outcome of this case. He showed some hostility toward the PMD, and intimated that the primary physician had been at once too detached and too intrusive in the care of the patient. He was especially confused about some of the medical and psychosocial aspects of patient management; and especially concerned about the medico-legal ramifications.

The Family: The family remained remote and uncommunicative during their son's hospital stay. The resident was under the impression they spoke no English, as they never communicated with him, or showed that they understood his verbalizations to them. However, the PMD stated that the father spoke English adequately, that the mother had good comprehension, and that they had often discussed their son's condition with him. Similarly, the resident was not aware that the family knew of their son's homosexuality; while the PMD insisted that they had full awareness of his sexual orientation. The mother appeared to mediate between father and son.

ISSUES:

What happens when there is a significant degree of alienation in patient, family, and referring physician from the system supposed to render aid?

What are the likely points for the system to fail patient and family?

What were the sources of patient, family, and PMD's alienation and hostility?

What was the view of hospital staff toward this patient and family?

What were the strengths and weaknesses of how the system responded to this patient and family?

What could be learned in terms of a more positive outcome from a similar hospitalization in the future?